

# **HIV/AIDS SERVICES IN MASSACHUSETTS:**

**Integrated Statewide Plan: 2008 Update to the  
Comprehensive Plan and the Statewide  
Coordinated Statement of Need (SCSN)**

**February 1, 2009**

## **Table of Contents**

<b>I.</b>	<b>Letter of Concurrence.</b>	<b>36</b>
<b>II.</b>	<b>Contributors.</b>	<b>40</b>
<b>III.</b>	<b>Introduction.</b>	<b>3</b>
<b>IV.</b>	<b>Where Are We Now?</b>	<b>3</b>
	A. Description of the State	
	B. Epidemiological Profile	
	C. Description of the History of State Response to the Epidemic	
	D. Assessment of Need	
	1. Introduction	
	2. HIV Medical Care Needs	
	3. Unmet Need	
	4. Gaps in Care	
	5. Prevention Needs	
	6. Emerging Trends Affecting Care and Service Delivery	
	E. Description of the Current Continuum of Care and Available Services	
	F. Collaboration among the Titles	
	G. Barriers to Care	
<b>V.</b>	<b>Where Do We Need to Go?</b>	<b>27</b>
	A. Shared Vision for Core Services within a Continuum of Care	
	1. Access to Care and Treatment	
	2. Support Services	
	3. Living Assistance	
	B. Shared Values for System Changes	
<b>VI.</b>	<b>How Will We Get There?</b>	<b>31</b>
<b>VII.</b>	<b>How Will We Monitor Our Progress?</b>	<b>34</b>
	<b>Attachment 1: Letter of Concurrence.</b>	<b>36</b>
	<b>Attachment 2: Routine HIV Counseling &amp; Testing of Pregnant Women, Clinical Advisory Update.</b>	<b>37</b>
	<b>Appendix A: List of Participants in the SCSN Process.</b>	<b>40</b>

## **I. Letter of Concurrence**

See Attachment 1.

## **II. Contributors**

See Appendix A.

## **III. Introduction**

The Ryan White CARE Act, established in 1990 and reauthorized in 1996, 2000 and 2006 (under the new name of the Ryan White HIV/AIDS Treatment Modernization Act, aka Ryan White HIV/AIDS Program) provides community-based coordinated primary care, allied health, and necessary support services to people living with HIV disease. Administered by the U.S. Department of Health and Human Services' Health Resources and Services Administration (HRSA), the Ryan White HIV/AIDS Program makes direct services, evaluation, training, and technical support capacity available through the five "parts" of the legislation. In order to improve the collaboration of these programs, HRSA has required that each state submit an updated Statewide Coordinated Statement of Need (SCSN)/Comprehensive Plan by February 2009.

In order to prepare this updated document, representatives from all Parts, including consumers, reviewed and amended information from the combined SCSN/Comprehensive Plan submitted to HRSA in 2006. After further revisions, this draft was distributed to providers and consumer representatives from all Parts for final comments. As required, the integrated document identifies epidemiological and service trends for people living with HIV/AIDS in Massachusetts, current and unmet needs, barriers to services, a vision for the future, how the state will get there, and how progress will be monitored. It serves as a shared understanding of need across all Parts and will be used for effective planning, efficient use of resources, and collaboration and coordination of HIV services throughout Massachusetts.

Representatives from all Parts have agreed on three broad goals for provision of HIV/AIDS services in Massachusetts. These goals include: (1) decreasing the number of new HIV infections, (2) increasing the number of people who know their HIV status, and (3) increasing the number of HIV-positive individuals leading healthier lives. Massachusetts has a history of effective collaboration across all Parts and seeks to expand such efforts. In this spirit, the grantees from all parts work together to provide services for those living with HIV in Massachusetts.

## **IV. Where Are We Now?**

### **A. Description of the State**

Geographically, Massachusetts is 190 miles long and 50 miles wide at its most distant points. Massachusetts is bordered by New Hampshire and Vermont in the north. In the south, Massachusetts is bordered by Connecticut and Rhode Island. To the east lies the Atlantic Ocean and to the west Massachusetts shares a border with New York. Massachusetts covers 10,555 square miles, making it the 44th largest state of the 50 states.

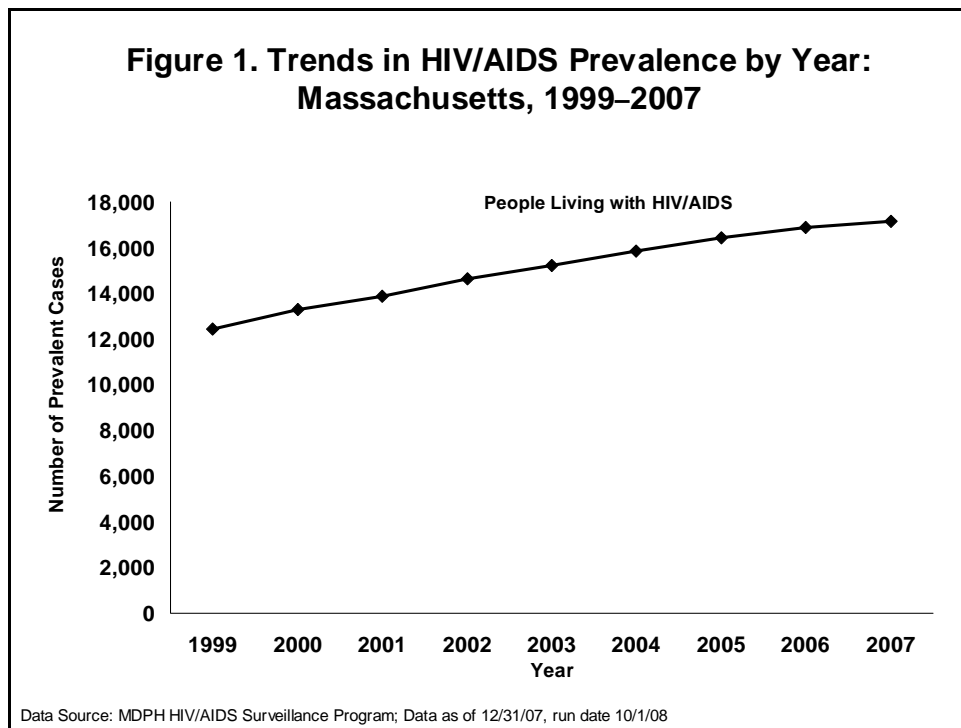
## General Demographics of the State

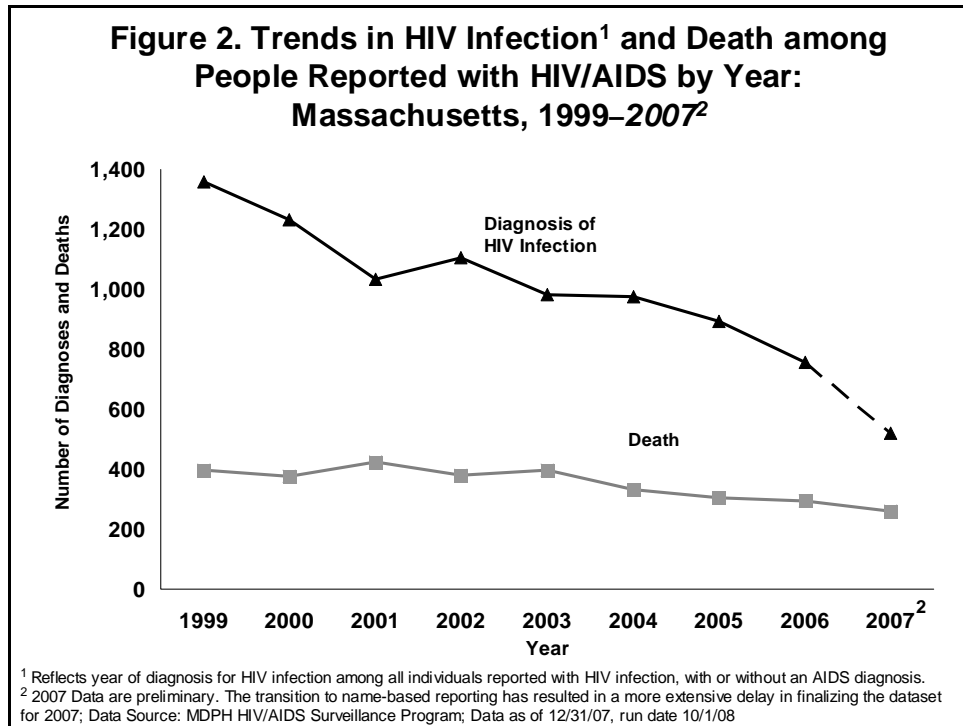
According to the 2005-2007 U.S. Census Bureau ACS 3-Year Estimate, Massachusetts had a household population of 6.4 million - 3.3 million (52%) females and 3.1 million (48%) males. The median age was 38.3 years. 23% of the population were under 18 years and 13% were 65 years and older. For people reporting one race alone, 84% were White; 6% were Black or African American; < 0.5% were American Indian and Alaska Native; 5 % were Asian; < 0.5% were Native Hawaiian and Other Pacific Islander, and 4% were some other race. 2% reported two or more races. 8% of the people in Massachusetts were Hispanic. 79% of the people in Massachusetts were White non-Hispanic. 14% of the people living in Massachusetts in 2006 were foreign born. 86% were native, including 64% who were born in Massachusetts. Among people at least five years old living in Massachusetts in 2005-2007, 20% spoke a language other than English at home. Of those speaking a language other than English at home, 34% spoke Spanish and 66% spoke some other language.

## B. Epidemiological Profile

The following is a description of trends and changes in the State's HIV/AIDS cases, including comparative analysis of the number of new AIDS cases reported; the number of people living with AIDS; and the estimated number of people living with HIV, based on the latest State HIV/AIDS Epidemiological Profile.

### HIV/AIDS Trends from 1999 to 2007:





Every year, there are more people living with HIV/AIDS in Massachusetts. In the past nine years, the number of people living with HIV/AIDS has increased as new HIV infection diagnoses exceeded the number of deaths among people reported with HIV/AIDS each year. From 1999 to 2007, the number of people living with HIV/AIDS increased by 38%.

#### *General Statistics*

- As of December 31, 2007, a cumulative total of 29,628 Massachusetts residents have been diagnosed and reported with HIV infection, with or without an AIDS diagnosis.
  - 42% (N=12,477) have died and 58% (N=17,151) are living with HIV/AIDS.
  - As of December 31, 2007,<sup>1</sup> there were 17,151 people known to be living with HIV/AIDS in Massachusetts.
- Including estimates of Massachusetts residents infected with HIV who do not yet know their status or who have not been reported, there are 25,000 – 27,000 individuals currently living with HIV/AIDS in the Commonwealth.
  - An estimated 21% of people with HIV infection do not know their status.

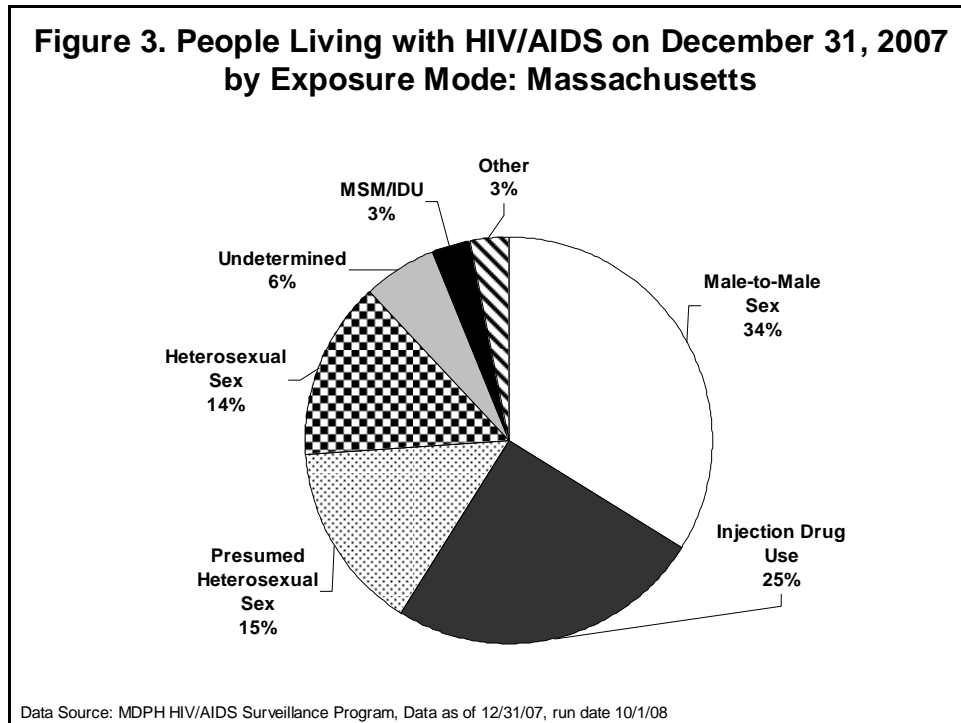
#### *Who is currently living with HIV/AIDS?*

- Forty-five percent of people living with HIV/AIDS in Massachusetts are white (non-Hispanic), 28% are black (non-Hispanic), 25% are Hispanic, 1% are Asian or Pacific Islander, and less than

<sup>1</sup> Previous editions of the Epidemiologic Profile presented people living with HIV/AIDS as of December 31 whereas this edition presents people living with HIV/AIDS as of October 1 due to the timing of this release. Future editions will return to presenting people living with HIV/AIDS as of December 31.

1% are American Indian or Alaska Native. In sharp contrast, black (non-Hispanic) and Hispanic individuals each make up 6% of the Massachusetts population.

- Male-to-male sex and injection drug use are the leading reported risks for HIV infection among people living with HIV/AIDS, accounting for 34% and 25% of all infections, respectively.



- Among **males** living with HIV/AIDS, 51% are white (non-Hispanic), 23% are black (non-Hispanic) and 24% are Hispanic.
- Among **females** living with HIV/AIDS, 28% are white (non-Hispanic) 41% are black (non-Hispanic) and 29% are Hispanic.

*Who is experiencing differential impact from HIV/AIDS?*

- With age-adjusted prevalence rates of 1,596 and 1,401 cases per 100,000 population, black (non-Hispanic) and Hispanic individuals are affected by HIV/AIDS at levels 12 and 10 times that of white (non-Hispanic) individuals (136 per 100,000).
- With age-adjusted prevalence rates of 2,033 and 2,036 cases per 100,000 population, black (non-Hispanic) and Hispanic **males** are each affected by HIV/AIDS at levels 9 times that of white (non-Hispanic) **males** (229 per 100,000).
- With age-adjusted prevalence rates of 1,228 and 847 cases per 100,000 population, black (non-Hispanic) and Hispanic **females** are affected by HIV/AIDS at levels 25 and 17 times that of white (non-Hispanic) **females** (49 per 100,000).

*Who is most at risk of HIV infection?*

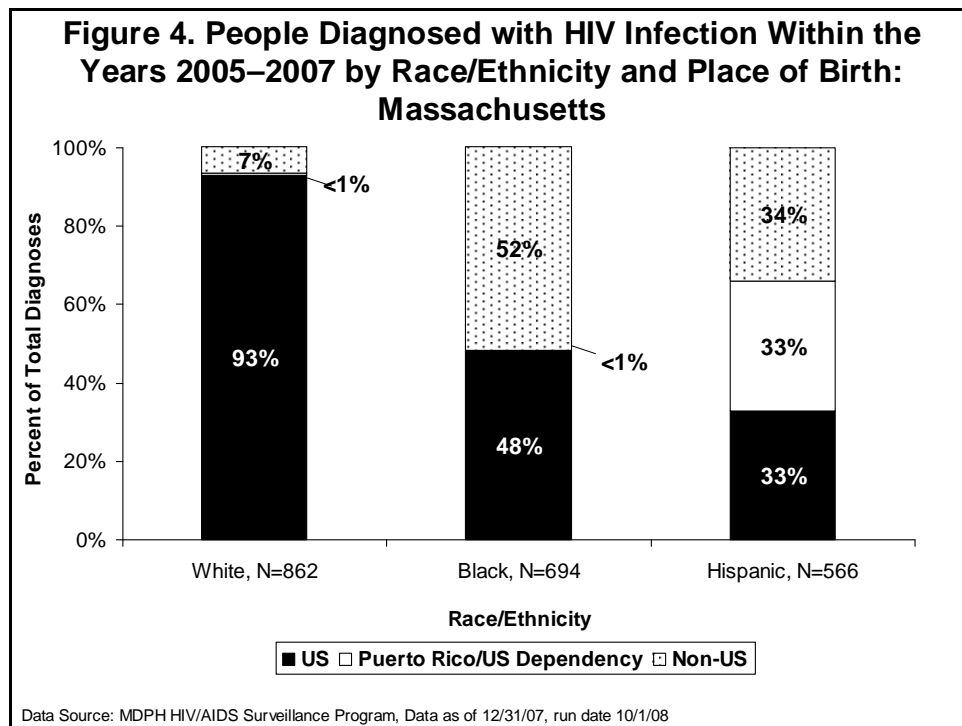
Trends in the distribution of HIV infection diagnoses from 1999 to 2007 are used to highlight populations at elevated risk of HIV infection. These trends, as well as the distribution of people who were recently diagnosed with HIV infection within the three-year period 2005 to 2007, provide useful information for planning and targeting HIV prevention programs.

- Of all people diagnosed and reported with HIV/AIDS in Massachusetts, 20,531 were diagnosed with HIV infection before 1999, 1,358 were diagnosed with HIV infection in 1999, 1,232 in 2000, 1,034 in 2001, 1,105 in 2002, 981 in 2003, 974 in 2004, 893 in 2005, and 757 in 2006. As of October 1, 2008, 520 HIV diagnoses were reported for 2007. This number will continue to increase as additional cases are reported, lessening the apparent decline in the number of HIV infection diagnoses over the past three years. As Massachusetts providers who report HIV diagnoses are still transitioning from code to name-based reporting requirements (effective January 1, 2007), the 2007 HIV infection diagnosis data are incomplete. Caution should be exercised when considering changes in trends for 2007 as it is possible that various populations may have been reported at different rates due to the potential for differential reporting by providers at the beginning of the new reporting system.
- From 1999 to 2007, the distribution of people diagnosed with HIV infection by gender varied between 68% to 73% male and 27% to 32% female.
- From 1999 to 2007, the proportion of HIV diagnoses ranged from 38% to 42% among white (non-Hispanic) individuals, from 29% to 35% among black (non-Hispanic) individuals and from 24% to 27% among Hispanic individuals.
- Among **females** diagnosed with HIV infection from 1999 to 2005, the proportion of black (non-Hispanic) females increased from 40% to 54%, while the proportion of white (non-Hispanic) females decreased from 29% to 16%. From 2006 to 2007 the trend reversed as the proportion of black (non-Hispanic) females decreased from 52% to 49% while the proportion of white (non-Hispanic) females increased from 22% to 25%.<sup>2</sup> From 1999 to 2007, the proportion of Hispanic females ranged from 24% to 31%.
- From 1999 to 2007, the proportion of HIV diagnoses where injection drug use was the mode of exposure decreased from 30% to 15%.
- Among **males** diagnosed with HIV infection, the proportion of HIV diagnoses with male-to-male sex as the primary reported exposure mode increased from 41% in 1999 to 56% in 2006 and then decreased to 47% in 2007.<sup>ii</sup>
- From 1999 to 2007, the proportion of HIV diagnoses among **females** exposed to HIV through heterosexual sex with partners of unknown risk and HIV status (presumed heterosexual sex) increased from 30% to 46%.

---

<sup>2</sup> As noted, caution should be exercised when considering changes in trends for 2007. Implementation of a new reporting system in 2007 may have led to differential reporting within race/ethnicity, gender and exposure mode as providers serving various populations reported at different rates at the beginning of the new reporting system.

- From 1999 to 2007, the proportion of people born outside the US among those with HIV infection increased from 19% to 30%.
- During the same time period the proportion of individuals born outside the US among **females** diagnosed with HIV infection increased from 28% to 43%.
- Fifty-two percent of black (non-Hispanic) individuals diagnosed with HIV infection within the three year period 2005 to 2007 were born outside the US, compared to 34% of Hispanic and 7% of white (non-Hispanic) individuals.



#### *Who is infected with HIV but does not yet know?*

People who already have AIDS when HIV infection is diagnosed (or who are diagnosed with AIDS within two months of HIV infection diagnosis) represent a population that may have first learned about their HIV status late in the progression of HIV disease. It is likely that people who are diagnosed with both HIV infection and AIDS within two months have been infected for more time prior to learning their HIV status than people who learn their status earlier in the course of infection.

- From 2005 to 2007, 677 people already had AIDS when HIV infection was diagnosed (or were diagnosed with AIDS within two months), representing 31% of the 2,170 diagnoses of HIV infection during this time period.
- Thirty-nine percent of people born outside the US who were diagnosed with HIV infection from 2005 to 2007 already had AIDS when they were diagnosed (or were diagnosed with AIDS within two months), compared to 28% of people born in the US and 31% of people born in Puerto Rico and other US dependencies.

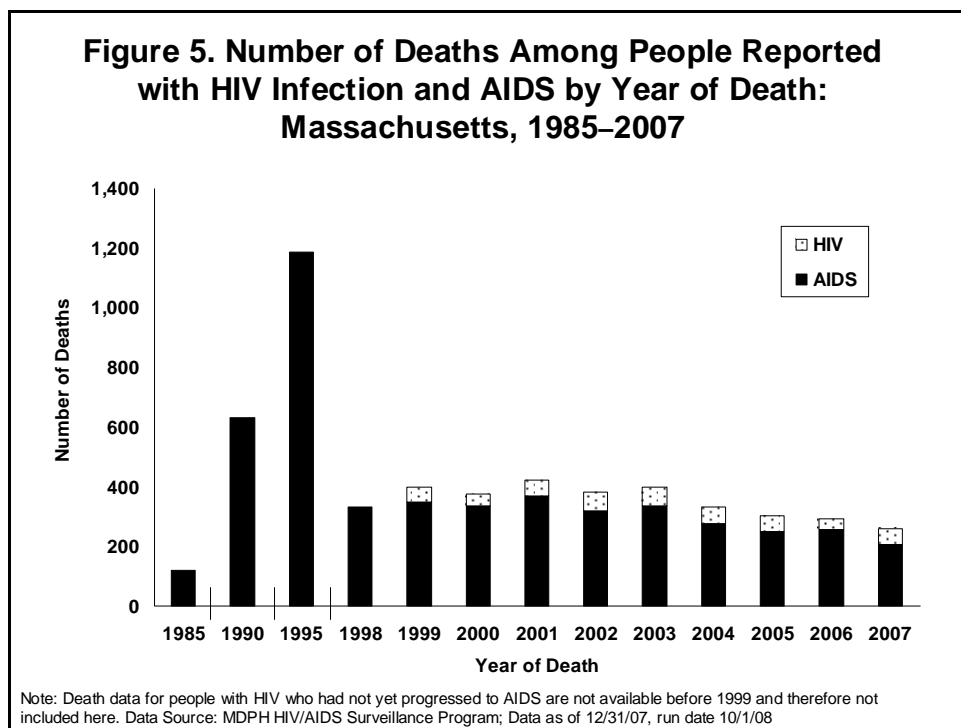
#### *How have patterns of AIDS diagnoses changed over time?*



- After reaching a plateau of incidence at around 900 new diagnoses each year from 1997 to 1999, reported AIDS incidence declined from 2000 to 2007, when 225 cases of AIDS were reported.
- From 1998 to 2006, the proportion of newly diagnosed AIDS cases among white (non-Hispanic) individuals ranged from 45% to 37% and then increased to 68% in 2007. The proportion of AIDS cases among Hispanic individuals from 1998 to 2006 ranged from 26% to 28% and then declined to 9% in 2007. The proportion among black (non-Hispanic) individuals ranged from 26% to 35% from 1998 to 2006 and then declined to 22% in 2007.<sup>ii</sup>
- For 11 years, from 1992 through 2002, the number of new AIDS diagnoses with injection drug use as the reported exposure mode surpassed the number of AIDS diagnoses with male-to-male sex as the reported exposure mode. From 2003 through 2007, the trend reversed with the number of new AIDS diagnoses with male-to-male sex as the reported exposure mode exceeding the number of those with injection drug use (141 vs. 32 in 2007).
- In 2007, the proportion of new AIDS diagnoses with male-to-male sex as the reported exposure mode reached 63%, more than double the proportion only a year before (29% in 2006).<sup>ii</sup>

*Who is dying with HIV/AIDS and how has this changed over time?*

- After reaching a peak of 1,212 in 1994 (data not shown), deaths among people reported with AIDS declined each year until 1998, when there were 332 deaths. (Deaths in people reported with HIV infection [non-AIDS]<sup>iii</sup> are not available prior to 1999 because HIV infection was not a reportable condition before that time.)



- From 2003 to 2007, the annual number of deaths of people reported with HIV (non-AIDS)<sup>3</sup> and AIDS declined each year to a low of 261 in 2007.
- The proportion of deaths among people with HIV (non-AIDS)<sup>iii</sup> of total deaths among people reported with HIV/AIDS increased from 12% in 1999 to 21% in 2007.
- The proportion of deaths among people reported with HIV/AIDS who were female increased from 24% in 1999 to 31% in 2007.
- From 1999 to 2007, the proportionate distribution of deaths among people reported with HIV/AIDS by race/ethnicity fluctuated without a clear trend. The proportion of deaths among white (non-Hispanic) individuals during this time period ranged from 47% to 55%, black (non-Hispanic) from 22% to 30% and Hispanic from 18% to 27%.
- From 1999 to 2007, the distribution of deaths among people reported with HIV/AIDS by exposure mode remained fairly stable, with roughly half of deaths each year in people with a primary reported risk of injection drug use and 16% to 22% in people with a risk of male-to-male sex.
- From 1999 to 2007, the proportion of deaths among people reported with HIV/AIDS with a primary reported risk of heterosexual sex (with partners with known risk and HIV status) ranged from 7% to 12%, of presumed exposure through heterosexual sex from 7% to 9%, of male-to-male sex and injection drug use (MSM/IDU) from 4% to 7%, and of other risks 1% to 3%.

## C. Description of the History of State Response to the Epidemic

In 1983, Governor Dukakis convened the Massachusetts Task Force on AIDS, chaired by then Department of Public Health (MDPH) Commissioner Bailus Walker. Composed of leading clinicians, researchers, epidemiologists and community advocates, the Task Force met monthly to develop, guide and plan for the Commonwealth's multi-faceted response to the epidemic. In 1985, the HIV/AIDS Bureau was established. AIDS planning and support was originally provided through the Health Resource Office.

From the beginning, the state has provided a variety of services throughout the Commonwealth of Massachusetts. Currently services range from prevention and education to HIV antibody counseling and testing, client services, health and support services. Through partnerships with community-based agencies, that emphasize commitment to the importance of multicultural health, the state is able to maximize the public's access to services that significantly improve the quality of life for people with HIV and AIDS, and their families.

The state strives to prevent the spread of the AIDS epidemic and the development of appropriate, cost-effective health and support services which will maintain patients in the least restrictive setting.

Please note: Effective January 1, 2009, the MDPH HIV/AIDS Bureau and the Bureau of Communicable Disease Control have merged into a single entity, the Bureau of Infectious Disease

---

<sup>3</sup> People with HIV infection (non-AIDS) refers to those who were reported with an HIV infection diagnosis and did not progress to AIDS before death.

Prevention, Response, and Services. The HIV/AIDS Bureau will retain a distinct identity as the Office of HIV/AIDS (OHA) in the new Bureau.

## D. Assessment of Need

### 1. Introduction

Planning, delivery, and assessment of comprehensive HIV health and support service needs is an ongoing process in the Commonwealth, organized in part around the timing of federal and state resource allocation schedules, but predicated primarily on the annual review of surveillance information and service utilization. These efforts engage broad components of the consumer and provider communities and colleagues in other state and federally financed HIV-related services. Determination of need thus becomes an iterative assessment of population and program-based trends as they intersect with: evolving clinical and behavioral understandings of the dynamics of the epidemic; changes in local, regional, and statewide social and economic circumstances; the capacity of the state and others to generate effective mechanisms for assessing unmet needs; and the perceptions of consumers and providers about relative priorities in environments of uncertainty and change.

There is a long history of ongoing and collaborative planning regarding emerging HIV service needs in Massachusetts. For purposes of this document, all available and proposed service needs assessments conducted by Ryan White HIV/AIDS Program grantees in Massachusetts were reviewed. Those assessments are briefly detailed below.

**Part A.** In 2008, the Part A Planning Council completed its annual report: *Assessment of Issues that Affect the Service Needs of People Living with HIV/AIDS in the Boston EMA, and Funding Streams Overview of Funding for HIV/AIDS Services in the Boston EMA, 2008*. This information was compiled from data contained in the FY2009 Ryan White Part A grant application and from additional research conducted by the Planning Council Support staff. Additionally, the BPHC AIDS Program has provided reports to the Council on: *Ryan White HIV/AIDS Treatment Modernization Act Part A Boston EMA Year 17 Client Service, and the Ryan White Part A Year 18* ).

In addition, under contract with the Part A Grantee, JSI and Suffolk University have written reports on health outcomes for Part A clients and consumer feedback on services within affected communities and subpopulations, and linkage across Ryan White-funded services, including:

- JSI Report: *Satisfaction Survey of Consumers of HIV Case Management, Food, & Peer Support Services funded by the Ryan White Program Part A in the Boston EMA, 2008*
- JSI Report: *HIV/AIDS Clinical Care Quality Assurance Project Trends in Clinical Performance & Clinical Outcomes at All Reviewed Boston Public Health Commission Funded Ryan White Part A Clinics 2001-2006*
- Suffolk Report: *Ryan White HIV/AIDS Treatment Modernization Act Boston EMA Part A (Title I) Programs: Outcomes Measurement Summary – Annual Outcomes Report FY 2006, September 2007*
- Suffolk Report: *Ryan White HIV/AIDS Treatment Modernization Act Boston EMA Part A (Title I) Programs: Impact of Part A Services on New Clients Over Time, January 2008*
- Suffolk Report: *Health & Quality of Life of PLWH in the Boston EMA Three- Year Cohort Study*
- Suffolk Report: *Ryan White CARE Act Boston EMA Title I Programs Outcomes Measurement Minority AIDS Initiative (MAI) FY06 (March 2006-February 2007)*

**Part B.** In the 2006 SCSN the result of four Part B sponsored comprehensive regional meetings (in which provider and consumer feedback around statewide needs was gathered) was reported out on. These meetings, along with the Suffolk University Voices of Experience Surveys (see Part A above), have continued to inform the needs assessment process for Part B in the state. Currently, the MDPH OHA, in conjunction with Part A grantee, is preparing a comprehensive statewide consumer survey, the format of which is being finalized, to be completed by the end of the calendar year 2009.

In addition, the MDPH Office of HIV/AIDS (OHA) contracts with eleven Service Coordination Collaboratives (SCCs) which replaced the former Ryan White consortia starting in FY 2006. As part of their contract agreements, each SCC is expected to assess the degree to which the service system within the SCC's coordination area is meeting the needs of consumers living in that area. These assessments focus on how the system as a whole is functioning. The determination takes into account the kinds of services being provided, including those that are not HIV-specific (e.g., mental health and substance abuse services). A regional consumer needs assessment can assist with this, as well as a survey of services offered by existing providers in the region, along with the eligibility criteria attached to those services.

**Part C.** Data from a clinical chart review (see HIV Medical Needs below), which covers all of the MDPH OHA-funded regional and affiliated primary care sites, most of the Part C funded programs, as well as a number of the Part A settings, has provided the most comprehensive view of cross-facility, cross-population, and cross-jurisdiction process of care and client health status information. Though started primarily as a CQI effort, the findings from these reviews continue to provide powerful statewide and local needs assessment information, including information about disparities, that help inform ongoing program development across services areas, from case identification to housing support. The chart reviews extract data from public sites, targeting Ryan White HIV/AIDS Program clients, and thus providing cross-sectional data on those clients with the greatest needs. These clients represent a diverse patient population with increased needs as compared to surveillance data alone. Clinical chart review data are supporting community and statewide processes of program development and resource allocation.

**Part D.** Massachusetts Community AIDS Resource Enhancement (MassCARE), the MDPH statewide program for women with HIV and their children and families, prepared program-specific needs assessment in 2006 as part of the re-application for funding.

In addition, based on anecdotal evidence from the MassCARE perinatal programs, the Massachusetts Pregnancy Risk Assessment Monitoring System (PRAMS) added new State-specific questions about HIV testing during pregnancy to its survey in 2007. Recently released preliminary data from survey has recently been released which shows that rates of HIV testing in pregnancy differ significantly depending on mothers' race/ethnicity, age and education levels. This information will inform continued efforts around routine HIV testing.

#### **Part F and SPNS.**

Each of these Parts conducted program-specific needs assessments. These needs assessments focused on a range of issues, from examining local health services' infrastructure to evaluating the general needs of people with HIV in a specific service or geographic area. The

In addition to these needs assessments, this SCSN has been developed using other existing quantitative and qualitative information including Massachusetts HIV and AIDS Surveillance Reports, the most recent Massachusetts Census Data and utilization reports from HIV-related programs from across the Commonwealth.

## **2. HIV Medical Care Needs**

Since 2002, John Snow Institute (JSI) has conducted biannual reviews of HIV/AIDS primary medical care in 21 sites. The clinical chart review data represents a cross-section of patients in Massachusetts with some of the greatest needs, being served in Ryan White HIV/AIDS Program-funded public facilities (sample size ranged from low of 981 in 2001 to a high of 1211 in 2003). Three cycles of review have been completed and seven years of data are available (2000 to 2006) for each participating site. In May 2008 a preliminary report was submitted which outlined findings in clinical performance and outcome measures that focus on prevention, screening and treatment in clinical care management.

### *Patient Characteristics*

For the period 2001 – 2006 the chart review data showed a population that was 58% ethnic and racial minorities. During the same period there has been a gradual increase in the proportion of foreign born patients from 19% in 2001 to 28% in 2006. Throughout the 6 review years, approximately 25% of patients sampled at all sites had MSM as a documented HIV risk factor. The proportion of patients with heterosexual transmission risk was around 55%. There has been a gradual decrease in the proportion of patients with documented IDU risk from 40% in 2001 to 29% in 2006. The proportion of patients with an AIDS-defining condition increased slightly from 54% in 2001 to 62% in 2006.

### *Outcomes*

From 2001-2006, overall clinical performance and outcomes improved across all sites in the chart reviews. Clinical performance in areas such as ART management, PCP prophylaxis, and CD4 counts met national guidelines. An impressive improvement was also observed in patient health outcomes, specifically viral suppression, likely reflecting enhanced ART effectiveness and ART management.

In evaluating aggregate performance on select clinical care measures by demographic subgroups, there were no consistent trends throughout the six review years to suggest disparity in care. For example, disparities in viral suppression rates by race-ethnicity noted in 2001 and 2002 were absent from 2003 onwards.

While this preliminary data seems to indicate that clinics funded with Ryan White dollars are meeting the medical needs of people living with HIV in Massachusetts, a better understanding of the gaps in service will be achieved by analyzing the newly acquired dataset from the state Medicaid program (see Unmet Need section below), which represents a much larger group of individuals being treated for HIV disease.

## **3. Unmet Need**

### *Estimation Methods*

While annual chart review data is collected, these data represent only those individuals in care and therefore do not provide a comprehensive measure of unmet need. In addition, an ongoing consumer survey project, while useful in identifying the unmet need and barriers of those who are sampled, again is not a comprehensive methodology for the purposes of the Unmet Need estimate. Therefore, the OHA has spent several years trying to obtain Medicaid data in order to complete the unmet need estimates. The OHA was finally successful this past year in obtaining Medicaid data and is in the process of completing the unmet need analysis.

Because the state HIV/AIDS Surveillance system does not collect the required variables to calculate the unmet need estimate, a single dataset approach would not be possible. Therefore the OHA is using analysis of existing datasets for the purposes of calculating unmet need. In addition, the OHA believes that this is the most accurate and comprehensive method available.

- **Population inputs:** HIV and AIDS data will be obtained from the HIV/AIDS Reporting System (HARS), the source of HIV/AIDS diagnosed and reported cases.
- **Care inputs:** Medicaid data and client data from the locally developed data collection system called Genuwin are being used to for the public care system. In order to account for individuals in the private care system, an estimate of the number of people living with HIV disease covered by private insurance will be calculated from The Healthcare Cost and Utilization Project's National Inpatient Sample (HCUP NIS). Rather than assume that all individuals living with HIV or AIDS who have private insurance do not have an unmet need, the estimate will be adjusted based on the care patterns seen in a sample for private insurance data sources. It is as yet unclear if these data will be made available to us.

#### *Assessment of Unmet Need*

As noted above, the OHA has recently obtained three years of Medicaid individual encounter data that will enable completion of unmet need estimates. Therefore, the remainder of this section presents the anticipated unmet need analysis:

- **Determination of the demographics and location of people who know their HIV/AIDS status and are not in care** - Based on the data that were requested, the OHA plans to calculate the following population specific unmet need estimates:
  - Gender
  - Race/Ethnicity
  - Age

Exposure category is also a variable of interest, but it is not collected by the state Medicaid and would require development of a link to the database used to report service utilization data to HRSA. Given the resources currently being used to transition to client level data, it is unclear if this will be feasible to complete for the first estimate. However, once the transition to client level data is complete, this variable will be included in the estimate. Zip code data will also be analyzed to help determine specific locations in the state where there are higher levels of unmet need.

## **4. Gaps in Care**

The comprehensive nature of service provision critical to optimizing health and opportunity for people living with HIV has been an enduring strength of the Ryan White program but has also has posed ongoing problems in terms of need determination and priority setting. The challenges of larger and more diverse populations living with HIV in constrained economic times requires more efficient and effective processes of characterizing critical needs.

Having more real-time surveillance information has improved the capacity of the OHA and others to compare service utilization with reported cases to grossly assess issues regarding populations that may be underserved within certain regions or service arenas. Furthermore, the establishment of a single unique identifier across the two largest Ryan White funders (Parts A and B) will allow for unduplicated assessments of program participation and for better understanding about access concerns and migration patterns in service utilization. Nonetheless, ongoing communication with the community continues to provide the OHA with the most up to date data on the HIV/AIDS service needs in the community.

- **Assessment of service needs, gaps, and barriers to care for people not in care** – As previously mentioned, the OHA has conducted both ongoing chart reviews as well as a consumer survey project to identify service needs, gaps and barriers to care. The chart review data showed overall high levels of primary care visits as well as CD4 counts. For primary care visits, no differences were noted among different subpopulations. However, differences were found among clients at certain providers located in different parts of the state. Further investigation into contributing factors for these differences will occur this year to identify any needed system modifications. For CD4 counts, non-US born individuals were more likely to have two or more CD4 counts at least three months apart than US born individuals, although the rates for both groups were high. In addition, a greater proportion of White non-Hispanic clients had regular CD4 counts than racial/ethnic minorities in 2005 and 2006; again, the rates for each group were high. As with primary care visits, differences were found among certain providers located in different parts of the state. In the Consumer Survey Project, “Voices of Experience” only 2% of respondents reported that they needed primary medical care but were unable to get it. Barriers noted included difficulty accessing service providers; providers were not helpful and did not know where to go for services. It is important to note, however, that both of these data sources reflect people in the existing system of care, underscoring the importance of successfully obtaining the Medicaid data in order to conduct a more extensive analysis of unmet need.
- **Efforts to find people not in care and get them into primary care** – OHA has several methods to assist in finding people not in care and getting them into primary care. First, OHA HIV counseling and testing contracts require that clients who test positive must be linked into primary care. Second, case management and support service funded contracts are required as part of their award to provide supported referrals to primary medical care for any clients not currently receiving medical care. This means that not only a referral is provided, a linkage to the service must be made to increase the likelihood that the client will show up for the appointment. Finally, the OHA works with a Statewide Consumer Advisory Board as well as regional SCCs. Both of these groups offer opportunities for consumers to identify any barriers that they may be facing in seeking care.
- **Use of the results of the Unmet Need Framework in planning and decision making about priorities, resource allocations, and adapting the system of care** – The results of the unmet need analysis will be utilized for planning, allocation of resources and addressing gaps in the existing system of care. In the past, analyzing existing datasets has allowed for prioritization of services to underserved populations, expansion of services in certain parts of the state, and encouraging partnerships to more efficiently utilize resources and enhance linkages. It is anticipated that past experience with integrating data analysis into program planning will help to optimize Unmet Need data analysis results.

## 5. Prevention Needs

In the last three years efforts to reduce the transmission of HIV in Massachusetts have been successful in a number of populations at risk, including injection drug users, heterosexual men and women. However, less success can be reported from work with members of communities of color, gay and bisexual men, and other men who have sex with men (MSM)

### *Communities of Color*

On December 1, 2007, MDPH released the first in a series of reports on the HIV epidemic in Massachusetts. This report, *An Added Burden: The Impact of the HIV/AIDS Epidemic on Communities of Color in Massachusetts* outlined the issues facing this population and suggested steps to address them. Since the beginning of the HIV/AIDS epidemic in Massachusetts, members of communities of color have been affected at rates grossly disproportionate to their representation in the general population. While only 6% of the Massachusetts population are black and another 6% are Hispanic according to Census figures, over 28% of people living with HIV/AIDS in Massachusetts are black (non-Hispanic), 25% are Hispanic, 1% are Asian or Pacific Islander. Persons of color are far more likely than white individuals to be living with HIV, black and Hispanic individuals being 11 and 9 times more likely to be HIV+ than white individuals. This rate of disproportion is greater among women of color. While approximately half of men recently diagnosed with HIV are non-white, 83% of women recently diagnosed with HIV are women of color. These levels of disproportion are also evident in rates of death among persons of color with HIV.

Immigrant and refugee populations are an increasing proportion of the Massachusetts HIV/AIDS epidemic, and the majority of all newly diagnosed cases among communities of color. Sub-Saharan Africa, the Caribbean Basin, and Central/South America are the major regions of the world from which these populations originate. Late diagnoses in these populations are common, with 36% of recently diagnosed non-US born individuals having an AIDS diagnosis within two months of initial diagnosis of HIV infection. In addition to the factors complicating access to services common to all communities of color, non-US born individuals may be facing the added burden of immigration issues, fear of action by federal authorities, family displacement, special employment concerns, and social isolation.

The following are recommended actions to address the impact of HIV/AIDS on communities of color:

- Expand the public health investment in programs serving members of communities of color so that it exceeds their relative representation in the epidemic
- Expand culturally-specific public information about HIV to build a greater level of knowledge about HIV risk, risk reduction, the utility of HIV testing, and the availability of HIV services among communities of color
- Expand social network outreach efforts to more effectively engage members of communities of color in preventive and testing services by relying on the trusting relationships that are a major source of resiliency in these communities
- Develop, test, and implement science-based prevention interventions that utilize the language, visual images, values, and traditions of various communities of color



- Expand the availability of needle/syringe access programs in locations likely to be utilized by members of communities of color
- Expand the representation of members of communities of color in the staffing of public health and medical programs
- Increase the availability of routine and rapid HIV testing in health care settings and other community locations likely to be utilized by members of communities of color
- Expand the availability of partner counseling and referral services to assist newly diagnosed HIV+ individuals to inform their partners of possible HIV exposure
- Continue and expand corrections-based health care and preventive services for HIV+ and at-risk members of communities of color.

*Gay and Bisexual Men and Other Men Who Have Sex with Men.*

On World AIDS Day 2008, the second in the series of reports on the HIV Epidemic in Massachusetts was released. *Inequitable Impact: The HIV/AIDS Epidemic Among Gay and Bisexual Men and Other Men Who Have Sex with Men in Massachusetts.* gay and bisexual men and other men who have sex with men (MSM) represent over 50% of HIV cases reported among Massachusetts men between the years 2004 and 2006, and 39% of all HIV cases reported during this period. These rates of new infection are striking in light of the fact that only 4.3-9.4% of Massachusetts men (18-64 years old) report having had sex with men in the past twelve months on standardized behavioral surveys over the past seven years. These impacts represent an inequitable rate of infection that is nearly 25 times higher for men who have sex with men than for men who report only having had sex with women.

This report recommends the following steps to address needs of this population:

- Expanded and more equitable investment of prevention resources directed toward MSM
- Ongoing epidemiologic and behavioral inquiry to understand the contexts and factors influencing sexual and other risk in MSM
- Further prevention intervention research and evaluation of emerging approaches to prevention of HIV among MSM
- Targeted intervention research and evaluation for the multiple subsets of MSM, including white men, men of color, and immigrant and refugee populations of MSM
- Ongoing research, in collaboration with national and international efforts, into promising biomedical approaches to prevention that may be useful to MSM, including post-exposure prophylaxis, pre-exposure prophylaxis, rectal microbicides, and circumcision
- Widespread free condom availability to MSM, including high school-age MSM
- Further development of interventions rooted in a sexual harm reduction approach and utilizing a sexual health framework, delivered with sufficient intensity and sufficient length to effect behavior change
- Interventions that utilize skill-building around disclosure/discussion of HIV status with partners and the negotiation of sexual harm reduction, including condom use
- Linkage of prevention programs directed to MSM with substance abuse treatment, mental health supports, and sexual violence and other trauma recovery services
- Targeted prevention interventions serving young MSM
- Targeted prevention interventions serving HIV+ MSM

- Prevention interventions serving serodiscordant couples
- Location of prevention interventions serving MSM in public, private, and commercial sexual venues, including Internet-based interventions
- Maintenance or expansion of current levels of HIV testing targeting MSM, including anonymous HIV testing
- Expanded screening and vaccination for co-occurring conditions among MSM, including sexually transmitted infections and viral hepatitis
- Maintenance of current access to medical care and antiretroviral therapies for HIV+ MSM
- Improved strategies for recruiting MSM into proven effective individual and group prevention interventions, including social marketing and social network outreach
- Greater volume of targeted public information, community-building, and other community-level prevention interventions
- Legal, educational, and policy-level interventions to reduce social barriers and stigma surrounding same-sex sexual relationships
- Enforcement of legal protections for gay, lesbian, bisexual, and transgender individuals
- Expanded involvement of faith-based communities in the support of gay/bisexual men and other MSM

## 6. Emerging Trends Affecting Care and Service Delivery

There are three primary trends that affect care and service delivery for people living with HIV/AIDS in Massachusetts. They include changes in the epidemiology of the HIV epidemic, changes in treatment access and options, and systemic changes in health care delivery both in Massachusetts and on the national level.

### *Changes in the HIV Epidemic*

As mentioned above, communities of color and men having sex with men are disproportionately effected by the HIV epidemic in Massachusetts.

- 28% of the people living with HIV in the state are black (non-Hispanic), 25% are Hispanic, 1% are Asian or Pacific Islander, and less than 1% are American Indian or Alaska Native. In sharp contrast, black (non-Hispanic) and Hispanic individuals each make up 6% of the Massachusetts population.
- With age-adjusted prevalence rates of 1,596 and 1,401 cases per 100,000 population, black (non-Hispanic) and Hispanic individuals are affected by HIV/AIDS at levels 12 and 10 times that of white (non-Hispanic) individuals (136 per 100,000).
- Among **males** diagnosed with HIV infection, the proportion of HIV diagnoses with male-to-male sex as the primary reported exposure mode increased from 41% in 1999 to 56% in 2006 and then decreased to 47% in 2007.<sup>ii</sup>

### *Changes in Treatment*

New and expanded treatment options, including increased options within existing drug classes, have resulted in more people living with HIV for longer periods. These treatments, however, are not a panacea. There are still many people who, for a range of reasons, have not benefited from new

treatments. Lack of access, adherence support needs, drug interaction, and drug failure all complicate the likelihood of long-term success.

As in the 2006 SCSN, changes in treatment continue to have a major impact on service delivery, resulting in the need for strategic long-range planning to address critical issues. These issues still include:

- a demand for a wider range of services for people at different stages of illness;
- a need for targeted services that meet the needs of an aging population;
- an increased need for chronic care management capability;
- an increased demand for access to new treatment options and appropriate monitoring capacity, and the need to assure equitable treatment availability;
- a need for increased benefits management and support services, including facilitation of entry or re-entry into the workplace, recovery support, and employment services;
- increased annual and lifetime costs for treatment and care;
- a need for support for active substance abusers;
- an increased need for treatment of co-morbidities;
- a need for studies of, and solutions for, the complications associated with using HIV medications while taking other prescription and non-prescription drugs;
- an ongoing demand for services related to the reintegration of incarcerated individuals;
- expansion of post-exposure prophylaxis (PEP) services;
- a need for continuous training of health care providers on new treatment guidelines, clinical applications, and strategies to support patient adherence to treatment regimens; including dental providers and dental/dental hygiene students.
- a need for continuous training of women's health care providers on new treatment guidelines, clinical applications, and strategies to ensure routine testing during pregnancy;
- an increased need for health related support services that support access to primary care;
- a demand for linkages with prevention providers to address the ongoing need for prevention services for positive individuals; and
- a demand for outreach to counseling and testing providers to help maintain a seamless continuum of care.

#### *Statewide and National Factors*

Improved services in geographic areas outside of greater Boston have resulted in changing patterns of care utilization. Dual service delivery systems have developed, with many newly diagnosed residents seeking HIV services locally while others continue to go to Boston for care and treatment. Additionally, more people with HIV are cared for through managed care organizations. This has resulted in changing patterns of service delivery, as well as fewer choices of specialty care and available therapies.

In 2006, two important legislative actions in Massachusetts impacted the healthcare of people living with HIV in the state. The first was Chapter 58 of the Acts of 2006, which was signed by Governor Romney on April 12, 2006. Commonly referred to as "Healthcare Reform", this Act provides access to affordable health insurance coverage to all Massachusetts residents through the modernization of health insurance laws, the removal of barriers to purchasing health insurance, redirection of existing

government assistance for uncompensated care to health insurance premium subsidies (institutions to individuals), and the expansion of state Medicaid eligibility for children and working adults. The second was Chapter 172 of the Acts and Resolves of 2006 allow for the purchase and possession of syringes and needles as of September 18<sup>th</sup>, 2006. While both of these had an overall positive effect for the prevention and treatment of HIV disease in Massachusetts, barriers still exist in both the areas of healthcare coverage and access to clean needles (see Barriers to Care section below).

## **E. Description of the Current Continuum of Care and Available Services**

### **Part A**

Part A provides emergency funding to metropolitan areas disproportionately affected by HIV. The Part A grant is administered by the Boston Public Health Commission. The Boston EMA HIV Services Planning Council, comprised of consumers, providers and representatives from other funding sources, conduct an bi-annual needs assessment, update a comprehensive plan, and prioritize, define and allocate Part A funding across HIV service categories. For FY 2008, the Boston Part A grant is \$13.2 million. It funds 11 categories of HIV direct care services with 94 programs within 51 agencies. These services include a full continuum of HIV medical care and support services. The Boston EMA also receives a separate Minority AIDS Initiative grant, totaling \$843,100 in FY 2008. Eight programs are funded to provide additional case management and peer support services that target PLWH from disproportionately impacted minority communities. The Boston EMA (Eligible Metropolitan Areas) has been a Part A recipient since the beginning of the CARE Act (FY 1991). The Boston EMA consists of seven counties in Massachusetts, and three counties in southern New Hampshire. Currently, the Boston EMA comprises over 350 cities and towns within these ten counties shared between two states and accounts for 78% of the total reported number of living HIV/AIDS cases from both states.

The continuum of care is supported by a variety of funding streams including the Centers for Disease Control (CDC), Massachusetts (MA) and New Hampshire (NH) general funds, City of Boston, Ryan White Parts A, B, C, D, F, and MAI (Part A), Dental Reimbursement, Special Projects of National Significance (SPNS) programs, Housing Opportunities for Persons With AIDS (HOPWA) funds, and Medicaid. The Boston EMA's comprehensive system of HIV care includes a fully accessible network of core medical services. Approximately 86% of all federal and state funding streams are directed towards ongoing medical and clinical care for PLWH.

### **Part B**

Part B provides grants to states to improve the quality, availability, and organization of HIV health care and support services. Part B dollars are administered by the Massachusetts Department of Public Health (MDPH) Office of HIV/AIDS (OHA), through its Health Services Unit, Planning and Policy Unit, Client Services Unit, and Consumer Office. Comprehensive services are delivered based on local assessment of need, community planning, and ongoing input from people who use the services. In FY 2008, the Massachusetts Part B grant award is \$19.5 million. Major accomplishments include creating greater access to new drugs and health coverage through the expansion of the Massachusetts HIV Drug Assistance Program, including implementation of an insurance purchasing program, an insurance continuation program, and an open drug formulary; innovative expansion of client services to support

increased access to medical care; and greater participation of people living with HIV in Massachusetts through the statewide Consumer Advisory Board (CAB) system.

### **Part C**

Part C EIS grants support outpatient HIV early intervention services for low-income, medically underserved people in existing primary care systems. Part C planning grants support communities and health care service entities in their planning efforts to develop high quality HIV primary care. There are 17 programs located throughout Massachusetts that receive Part C monies. Of those 17, 16 receive EIS grants and 1 receives a planning grant. Consistent with the Part C program expectations, Massachusetts' grantees use their funding to provide high quality, primary care services to persons living with HIV/AIDS who might not otherwise have access to this care. These services include HIV counseling, testing, and support services; early intervention and primary medical care; diagnostic radiology; referrals to specialty care and inpatient care; behavioral health and substance abuse treatment services; case management; interpreter services; and coordination with social services.

### **Part D**

Part D programs focus on the development and operation of primary care systems and social services for women, infants, children, and youth with an additional focus on linking these care systems with HIV research and clinical trials. In FY 2008, Massachusetts received \$2.7 million dollars for Part D programs. Massachusetts is home to four Part D grants: the Boston Pediatric and Family AIDS Project (BPFAP), which serves children and families in the Boston area and is administered by the Dimock Center; MassCARE (Massachusetts Community AIDS Resource Enhancement) which is administered by the Division for Perinatal, Early Childhood and Special Health Needs of the MDPH and serves other cities across the state including Brockton, Chelsea, Holyoke, Lawrence, Lowell, New Bedford, and Springfield, as well as broad regions of the state through its three perinatal centers serving HIV+ pregnant women and two active consumer networks, the Family Advisory Network and the new Teen and Youth Advisory Network; Latin American Health Institute, which coordinates comprehensive services, including case management, client advocacy, support groups, and medical care for adolescents in the Boston area; and Justice Resource Institute, which is an adolescent specific grantee.

These funded programs provide coordinated HIV services and access to research for children, youth, women, and families. Populations served are primarily minority with a high percentage of recent immigrants. Among women, the exposure category is primarily heterosexual sex transmission and among children and youth it is perinatal transmission. These services are delivered through a network of pediatric specialty and primary care providers. Client based services funded through Title IV include ensured access to clinical trials, community-based primary care, pediatric specialty care in community-based settings, and intensive family-focused case management services for both infected and affected individuals. Funds are also used to support consumer participation in activities and family-to-family support events that occur throughout the year.

MassCARE also funds education and training for providers within the network as well as to other providers throughout the state in targeted communities. In addition, MassCARE offers treatment information and guidelines to women's health providers through its statewide Perinatal HIV Provider Information Line.

## **Part F**

Part F funds two specific programs: (1) a national network of AIDS Education and Training Centers that conduct clinical HIV education and training programs for health care providers, and (2) a dental reimbursement program that assists accredited dental schools and post-doctoral dental programs with uncompensated costs incurred in providing oral health treatment to HIV-positive persons.

The New England AIDS Education and Training Center (NEAETC) provides training on HIV-related issues to physicians, nurses and nurse practitioners, physician assistants, mental health professionals, dentists, and other health care providers throughout the six-state region. In addition, the NEAETC conducts ongoing training needs assessments through: surveys of program attendees; regular review of program content and format for relevance to the most recent research and clinical findings; consultation with faculty, consumers, and advisory board members; and program participant evaluations.

Tufts University School of Dental Medicine, Boston University Goldman School of Dental Medicine, Harvard University School of Dental Medicine, Children's Hospital dental clinic, and Boston Medical Center provide coordinated dental services for those living with HIV/AIDS seeking treatment at their respective school clinics. The unreimbursed costs associated with providing for these services are provided, in part, through the HIV/AIDS Dental Reimbursement Program (Part F). At all five sites, patients received dental care in the schools' general and specialty clinics (note: faculty practice and some specialty clinics do not participate in Part F), with over 60% of all HIV/AIDS patients receiving free care. Over the past several years the level of reimbursement to Part F programs has decreased from a high of about \$.80 on the dollar to approximately \$.34 on the dollar. This has resulted in a reduction in the scope of services provided at some of the sites and a dollar limit on the total services per patient per year. Part F dental reimbursement providers have been the safety net for the Part A/DPH dental program especially with regard to specialty services and these limitations are becoming a barrier for some specialty care.

## **SPNS**

There are three Special Projects of National Significance in Massachusetts. Two programs focus on population and service delivery concerns. The third SPNS project is funded under the Oral Health Initiative which became effective in August 2006 and is a five-year project wherein 15 programs and an evaluation center received funding for developing, implementing, and evaluating oral health delivery models that can be replicable and sustainable.

## **F. Collaboration among the Parts**

Massachusetts' success in slowing the AIDS epidemic can be credited to its ability to assess the needs of people living with HIV, and to develop effective service delivery strategies. Collaboration between Parts has served to strengthen this process. Together, the programs funded under each Part have addressed the needs of those affected by HIV/AIDS by working with planning councils, SCCs, consumer advocacy boards, and inter-agency groups.

One of the strengths of the HIV service delivery system in Massachusetts is the collaboration across Parts. Highlights of these partnerships include:

- All Parts are currently represented on the Part A Planning Council.
- Representatives from different Parts participate in the planning of the biannual statewide HIV services conference.
- Parts A and B coordinate the data reporting procedures for all providers through the development of common service definitions and service units, and the establishment of common service codes to ease the requirements of multiple funding sources.
- Part B funded SCCs include representatives from other Parts providing services in their coordination areas.
- Parts A and B jointly procure case management services across the state.
- Parts A, B, and D have adopted and now utilize common standards of care for HIV case managers.
- Part B and D developed a Clinical Advisory update on routine HIV counseling and testing of pregnant women which was distributed in June of 2008, and are working together to develop strategies to improved prenatal HIV testing throughout the provider community (**See Attachment 2**).
- The Part F funded AETC provides education and training, as well as technical assistance, for Part C providers.
- The MA HIV Surveillance Implementation Team, first organized in 1998 was reconvened with some new member in 2006 to develop a plan to implement name-based HIV case reporting in MA. Changes to 105 C.M.R. 300.000 authorize the collection of names of persons diagnosed with HIV for surveillance purposes. These regulations became effective January 1, 2007.
- Parts A and B, along with the city of Boston and state and county HOPWA (Housing Opportunities for People with AIDS) administrators, meet on a regular basis to coordinate HIV-related housing services.
- In preparation for client level data (CLD) reporting to HRSA, Part A, Part B, and Part D grantees in the state have been meeting to develop a coordinated response to meeting the CLD reporting needs. This process has included identifying both long term needs of centralizing and streamlining data collection as well as identifying shorter term needs of transitioning to CLD.
- In the past, representatives from all Parts have met together several times to discuss Ryan White reauthorization and will be doing so again in 2009.
- Representatives from all Parts are represented on the Scientific Advisory Board of the Massachusetts HIV Drug Assistance Program.
- Parts A and B have begun exploring new possibilities for coordinating client services.

- The four Part D grantees meet monthly and have collaborated with each other on several conferences for consumers. “Teen Fest”, its second statewide Part D conference for HIV-positive and affected adolescents and youth, was held in April 2008. Planning is underway for a Youth Advisory Board to provide consultation to the Part B program.
- Part A, B and D are collaborating on upcoming data collection requirements for HRSA’s new client level data to be implemented in 2009.
- Outcome measures developed by Part A are also utilized by Parts B, C, and D.
- Parts A and B have been collaborating on development of quality assurance standards and measures for all client services. Existing standards of care have been consolidated into a single set of universal standards that now apply to all providers funded for services through the Ryan White HIV/AIDS Program Part A, Part B, and MA state funds. Parts A and B recently updated the standards to reflect evolving best practices in clinical and non-clinical settings.
- Within the EMA, the combination of all Ryan White dollars contribute 77% of their funding towards core medical services with a majority being used to fund the state ADAP program, outpatient and ambulatory health services, and critical medical case management services.

## **G. Barriers to Care**

There are many barriers that contribute to the difficulty faced by people living with HIV in accessing adequate HIV services in Massachusetts. They include:

### Socio-Economic Barriers

Limited financial resources, lack of access to affordable housing, cuts in social welfare entitlement programs, and inadequate health insurance, including prescription coverage, present major barriers to low income individuals seeking to access essential HIV-related services. These fiscal barriers are often compounded by the additional challenges of substance abuse, multiple HIV diagnosis in a family, and an array of mental health challenges which all contribute to the difficulty of people accessing services.

### Cultural/Racial Barriers

Insufficient access to a broad comprehensive health care and social service system creates barriers to service for African-Americans, Latinos, Native Americans, Asians, Haitians, Portuguese speaking populations, and recent immigrant groups, including native Africans. Furthermore, language skills, educational attainment, and economic positioning (lower skilled employment) also create hurdles for navigating the complex system of care. Therefore, there continues to be a need for health and social service providers to improve their ability to provide culturally appropriate and competent care to people of color, gay and bisexual men, lesbians, transgender individuals, adolescents, deaf individuals, and people whose first language is not English. Moreover, there is a need for existing culturally-based organizations to develop their HIV service capacity, especially since there are PLWH who know their status but are not in care, which will eventually present a challenge and additional cost to the service system.



### Geographic Barriers

Patterns of care in Massachusetts are fluid and complex. While there are increasing options for people in suburban and ex-urban areas, those in isolated rural areas (note: not just those in isolated rural areas, e.g. New Bedford) continue to struggle with lack of adequate choice in medical care, including access to clinical trials, within a reasonable distance. This is particularly true in Western Massachusetts, where transportation systems are inadequate and in Provincetown, where the nearest hospital is fifty miles away. Provincetown, on outer Cape Cod, has the highest rate of infection of any town or city in the state.

### Stigma and Fear of Disclosure

Both these factors continue to be cited as barriers to care by providers and some consumers, as noted in the Suffolk University survey and other consumer interviews. Some HIV-infected individuals are afraid of disclosure because it will affect their legal or immigration status, others are afraid because of potential consequences of disclosure in their community or home (e.g. high rates of discrimination, abuse, and domestic violence). This is especially true for immigrant communities, drug addicts, adolescents, and people living in small towns. The degree of actual stigmatization encountered by an individual or feared by an individual ranges from seeking health care locally to issues of disclosure to one's healthcare providers, family and social network.

In addition, the MDPH OHA and its partners continue to try to understand the more subtle levels of stigma that exist for people living with HIV through a stigma project being conducted by the Harvard Law Project.

### Legislative and Policy Barriers

Several ongoing political issues complicate efforts to provide integrated care to persons living with HIV and those at high risk for contracting HIV. Notable among these issues is the continuing legislative restriction on the creation of new needle and syringe exchange programs. These programs are critical to providing entry into care for active injection drug users. Existing authorizing legislation allows for the creation of up to ten programs, but initiation of a needle exchange program requires local approval. As a result of these restrictions, only four needle exchange programs currently exist in Massachusetts. An amendment to the authorizing statute that would allow MDPH to establish new programs with local input, but not local approval, was vetoed by our Governor. Chapter 172 of the Acts and Resolves of 2006 allow for the purchase and possession of syringes and needles as of September 18<sup>th</sup>, 2006, but broader access to sterile syringes through needle exchange programs remains an issue for those individuals who cannot afford to purchase sterile syringes.

Other policy barriers to care include the recent enforcement of strict criminal background checks on all publicly funded direct-care staff. This policy limits the involvement of community members as front-line providers. In addition, ongoing constraints of Federal immigration law pose similar difficulties for provider agencies as they attempt to employ culturally competent staff. Lastly, the shift in prioritization of funding from support services to primary care significantly affects access to primary care because the support services are what help the most vulnerable populations get into and remain in primary care.

Under the legislative requirements of the Ryan White HIV/AIDS Program, the Core Medical Services requirement stipulates that all Ryan White funded parts must direct at least 75% of Part A funds towards a set of "core medical services" and no more than 25% towards support services. Within the region, this requirement is met and exceeded when all HIV-related funding is accounted for. The

investment of state and other federal resources have been used to develop and maintain a comprehensive system of core medical services. This extensive funding, along with the availability of comprehensive insurance coverage, has mitigated the need for 75% of Ryan White dollars to be used for core medical services. If the region is not granted a continuation of its FY 2007 and FY 2008 waiver, the mandate that 75% of all funding be allocated to core medical services will have a detrimental impact on the continuum of care for consumers. By limiting the ability of local planning bodies to allocate dollars where they are needed, the flexibility to respond to the epidemic is diminished. This could specifically affect the Boston EMA, which under the waiver has allocated 46% of the Part A funds to be spent on core medical services and 54% of Part A funds to be spent on health-related support services. If the waiver is not granted, the health-related support services will be heavily impacted by the shortage of funding, which would affect the continuum of comprehensive care.

#### Restrictive Funding Streams

Because programs in Massachusetts are funded in several different ways, the requirement that certain monies be used only for certain activities impedes the provision of a seamless continuum of care. When providers are restricted, consumers seeking to access services are unfairly affected. Additionally funding for research studies has historically provided the infrastructure in many sites for provider education, testing, counseling; patient support, education, and clinical care for HIV infected pregnant women. The funding for these studies has been drastically decreased and, in some cases, discontinued. This will dramatically affect the ability of obstetric service providers to prioritize perinatal HIV testing.

Another factor that continues to affect the service delivery system is the reduction in available resources for HIV related care and support services. Reductions over the past several years on both the state and federal levels have drastically affected the ability of service providers to maintain a seamless continuum of care for individuals living with HIV.

#### Provider Staff Capacity

Providers of HIV services usually work long hours at difficult jobs, with limited compensation and training in return. Provider agencies need to be able to pay their staff more money and offer their staff more training opportunities. As it stands, providers are faced with retention problems, burnout, and apathy among staff because the incentives to stay and do this work are few. Flat funding is simply not meeting the needs of these critical service programs. When staff turnover becomes an issue, seeking services may feel reluctant to access those services because of their perception that the staff is abandoning them. Staff capacity issues also lead to inconsistent quality assurance mechanisms, which in turn affects service provision. Recruitment of new dental providers is difficult due to the low level of reimbursement as compared to a dentist's usual, customary, and reasonable fee schedule. Limitations also exist in finding providers who participate in the MassHealth dental program for Masshealth eligible clients. Since Part A dental is payer of last resort, clients who are eligible for MassHealth dental must receive services from a provider participating in both programs. The Part A/DPH dental program has negotiated for expanded dental services for PLWHIV under the category of medically necessary dental services.

#### Reporting Requirements including Client Level Data Collection

Reporting requirements often prove quite burdensome for providers who are compelled to meet the requirements of multiple funders without adequate funding to allocate for administration. Complicating matters for providers is the lack of consistent fiscal years across funding streams that leaves providers faced with reporting periods that do not correlate to other data collection periods. The additional reporting requirement that the new CARE Act Data Report will mandate only adds to this burden. As

a result, these requirements often force providers to divert their dollars and attention away from direct care and towards administration.

All Ryan White funded agencies have been collecting client-level data over a number of years to improve monitoring and quality management activities. The new HRSA client level data reporting requirement creates a number of barriers towards providing access and quality care for PLWH, such as: 1) the need for all providers to convert to a new client code identifier to avoid multiple codes for one client within an agency, 2) ensuring that existing agency data collection systems are compatible with the required data elements to be captured, 3) increased reporting burden on providers, and 4) assuring that client confidentiality is maintained.

### Housing Instability

A major barrier to entering and remaining in care for PLWH is stable housing. Complex drug regimens, keeping physicians' appointments, and having a safe, secure environment require stable housing. Stable housing for PLWH in the Boston EMA is problematic, particularly since people are living longer with HIV and the need for housing continues to grow, but resources to provide that housing have not. The lack of access to stable, affordable housing is a significant barrier to entering and remaining in care.

### Mental Health

Among PLWH, psychological distress poses a significant barrier to care. Many people delay accessing care because of fear, depression, and anxiety about their serostatus. The increase in co-morbidities of mental health and HIV/AIDS means that consumers entering care present with a much more complicated set of interconnected issues than in earlier years of the epidemic, and with a wide array of service needs.

### Aging

With the help of treatment, consumers are living longer and fuller lives. With this change comes the need to cater to an aging and older infected population, which will need increased access to care and additional support. Services for consumers will have to expand their knowledge and services to address the needs of an older population, aside from providing HIV-related assistance.

### Co-morbidities

Consumers will face more complex health challenges, as they might develop opportunistic infections in addition to aging illnesses (e.g. cardiovascular disease, diabetes, cancer). This increase in co-morbidities will pose a challenge to identifying symptoms from the different diseases, and in creating treatment regimens for multiple diseases. Furthermore, since treatment for HIV/AIDS has existed for about 20 years, there are still unknown long-term side effects to lifetime use of antiretroviral medications, and the type of care that will be needed.

## **V. Where Do We Need to Go?**

### **A. Shared Vision for Core Services within a Continuum of Care**

Access to necessary services for people living with HIV is the first priority for planning in

Massachusetts. This includes access to clinical care, as well as those services that help people living with HIV maintain their clinical care by reducing barriers and facilitating access. The following is a list of services that are prioritized, in no particular order, for planning in Massachusetts.

## **1. Access to Care and Treatment**

### **a. Primary Medical Care**

A significant number of people currently being served by the Ryan White CARE Act services are uninsured or underinsured. Limited coverage means they may face high deductibles and co-pays, spend-downs for eligibility, and limitations on covered drugs and mental health services. Continued access to primary care and the drug assistance program, as well as other health care coverage options, are needed to address a critical gap in access to HIV care and treatment. In addition, a full range of primary and subspecialty care, including obstetrics/gynecological care and health maintenance services, must be accessible to people at all stages of HIV disease.

### **b. Payment for Drug Therapies**

Massachusetts must continue to ensure that people living with HIV have access to essential drug treatment options, and that efforts continue to be made to guarantee access to state-of-the-art treatment and prophylactic drugs, along with drug adherence support, regardless of ability to pay. Further, the ongoing ADAP crisis in Massachusetts draws away every new dollar from other necessary, underfunded services, which only compounds existing barriers to access for people living with HIV in the Commonwealth.

### **b. Dental Services**

Comprehensive dental care continues to be an essential service need for people living with HIV. Loss of benefits, discrimination, low reimbursement rates, and lack of providers willing to treat people with HIV continue to result in inadequate dental care.

### **c. Substance Abuse Treatment**

A range of substance abuse services, including counseling, support groups, and relapse prevention provide substance abusers with a means to combat their addictions and ease into recovery.

### **d. Mental Health Services**

Treatment changes are complex and their effects on individuals are often unpredictable. More people will need assistance in coping with complex treatment regimens as well as the changes in their health status over time. A range of programs is needed to help individuals and families cope with the range of psychosocial issues arising from being infected with or affected by HIV. These services also must be made readily available to non-English speakers.

### **e. Managing Co-Morbidities**

More and more people living with HIV are finding themselves having to manage a dual diagnosis of HIV and substance abuse, hepatitis C, or a mental health disorder. However, despite this increase in dual or multiple diagnoses, services to address the needs of individuals living with these diagnoses have been slow to keep up. For individuals with an HIV and substance abuse diagnosis, a focus on abstinence based models, as opposed to models based on harm reduction, has made it more difficult for providers to prevent the spread of HIV among

substance users. This gap in services affects providers' ability to provide high quality, consistent medical care to people living with HIV who use substances.

**f. Clinical Trials**

Access to many unapproved treatments is available only through participation in clinical trials. Access to clinical trials begins with availability of trials, but also includes aggressive outreach for enrollment and ongoing support to ensure participation. It is essential that clinical trials be available to all populations, including women, people of color, adolescents, substance abusers, and people over the age of fifty.

**g. HIV Counseling and Testing**

In keeping with one of the goals that provides a basis for this document and for services in Massachusetts, it is essential that more people are encouraged to know their HIV status. Access to care and treatment, along with critical prevention methods, are conditioned upon an individual knowing his/her status.

**2. Support Services**

**a. Case Management**

This service is consistently identified as one of the most needed and most highly utilized. This is particularly true for women and people who have complex social and medical needs. Case management is needed at all stages of disease progression, as each stage presents particular challenges and choices.

**b. Complementary Therapies**

Alternatives to traditional Western medical approaches, and acupuncture in particular, are important adjuncts for the treatment of HIV symptoms and for the amelioration of side effects from specific treatments. Acupuncture is also effective for relief of pain associated with HIV infection, as well as adherence to treatment regimens.

**c. Food and Nutrition Services**

The nature of HIV disease progression requires communities to offer a range of food delivery options, including home delivered meals, congregate meals, and food-pantry style services. New treatment options also demand careful adherence to meal 'time-tables' and sound nutrition to maximize the effectiveness of combination therapies. Additionally, for many, these needs are compounded by the decrease in food stamp availability and support through other entitlement programs.

**d. Peer Support**

This service has emerged as an effective mechanism for helping people living with HIV cope with a variety of issues, including isolation and stigma, disclosure, and acceptance of HIV status. Peer support services include support groups, individual peer counseling, social support, educational programs, and evidence-based group-level interventions.

**e. Transportation**

In urban, suburban, and rural areas, the lack of adequate, accessible, and affordable transportation systems continues to interfere with the ability of people living with HIV to access the services they need. This is particularly true for families with children and for

individuals who are entering or re-entering the workforce.

**f. Legal Services**

The increased complexity of a range of legal and financial issues—including benefits eligibility and counseling, disability and employment issues, permanency and custody planning, and immigration issues—emphasizes the continuing need for quality services across the Commonwealth.

**g. Prevention and Education Services**

Many individuals with HIV are now living longer and fuller lives. In order to assist them with living healthier lives, providers will need to help individuals address the issues associated with co-infection and will serve as a resource for educating HIV-positive individuals about the risk of transmitting the virus to others. In addition, because of the increasing breadth and complexity of treatment options, broad-based education for medical providers, social service professionals, and people living with HIV has never been more important. Understanding and accessing treatment information, including the importance of drug adherence, is critical to slowing HIV progression. Making this information accessible to people of varying literacy levels and/or to those for whom English is not their first language is especially important.

**3. Living Assistance**

**a. Housing Related Services**

Housing is one of the most important services provided for people living with HIV. To meet varying needs, a range of services must be offered to help people locate, maintain, and/or retain housing. In addition, housing efforts must include the creation of supported housing programs throughout the Commonwealth. The reallocation of HOPWA funds across the Commonwealth has also complicated matters.

**b. Home Care/Life Skills Advocates**

Despite encouraging trends, there continue to be significant numbers of people living with HIV and their families who need a range of home health supports, including nursing, homemaking services, hospice care, respite care, and life skills advocacy.

**c. Adherence Support**

Many factors, including real or perceived symptoms associated with taking HIV medications, the challenge of keeping up with a very strict regimen, the number of drugs necessary to manage side effects, and various social and personal issues, such as work schedule and privacy, have made it difficult for many clients to adhere to their medication regimen. In order to adhere, many clients must rely on an adherence case manager, a nurse, or volunteers trained to provide them with the necessary support, e.g., emotional support or a reminder phone call to comply with prescribed medications and avoid the depressing prospects of coping with multiple side effects.

**B. Shared Values for System Changes**

Since 1989, Massachusetts statewide HIV planning has adhered to a set of Guiding Principles outlined in the first MDPH *MOVE AIDS* Report. Even in the face of diminishing resources over the past several years, these principles continue to inform our understanding of epidemiological trends, continuing service needs, and barriers to services faced by specific populations. They are:

- **Availability:** The supply and type of service is adequate to meet identified needs.
- **Acceptability:** Consumers achieve a maximum level of satisfaction with the availability, accessibility, cost, quality, continuity, and comprehensiveness of the service delivery system.
- **Accessibility:** The population or segment of the population is able to obtain the available services, which are designed to be easily obtained.
- **Coordination, Continuity, and Integration:** There is a system of care that integrates different services in a coordinated and continuous way.
- **Comprehensiveness:** Services are provided in a thorough manner that meets the comprehensive needs of the individual through direct service provision or a supported referral process. The delivery system is capable of addressing a continuum of health, medical, social, developmental, and educational needs experienced by those infected and affected by HIV.
- **Community-Based, Consumer-Oriented and Family-Centered:** Consumers are included in service planning, and services are delivered in a setting close to the consumer's community. Community resources are developed and coordinated to respond to consumers' varying individual and family needs. Consumers and family members are treated with respect, with their knowledge, skills, and life-challenges acknowledged by service providers.
- **Cost Effectiveness:** Services are provided in a manner that minimizes expenses and maximizes health outcomes.
- **Cultural Competency:** These principles become embodied in services when they are delivered by a diverse staff who are culturally competent, well versed in the language and cultures of program clients, and supported, well-trained and knowledgeable about current treatment and service options.

## VI. How Will We Get There?

### Goals & Objectives: 2009-2011

Massachusetts' success in slowing the AIDS epidemic can be credited to its extensive and expert consumer/provider partnerships, which assure ongoing and accurate assessment of the changing needs of people living with HIV and the efficient development and dissemination of effective service delivery strategies. Collaboration between Ryan White HIV/AIDS Program Parts has served to strengthen this process. Together, the programs funded under each Part have effectively determined the needs of those affected by HIV/AIDS by working with planning councils, SCCs, consumer advocacy boards, and through inter-agency mechanisms.

Since there are overlapping jurisdictions for Parts A and B in Massachusetts, coordinated efforts regarding resources and services are crucial. There are 7 of the Part B Service Coordination Collaboratives that fall within the Part A Boston EMA, so it is particularly critical that the OHA play a central role in the review of available services and the prioritization of service categories as established by Title I during their resource allocation process.

This Comprehensive Plan relies on coordinated data collection activities and standards of care between Parts A and B to inform priority setting and allocation formulas. Both the goals of the Part B program and the needs of people living with HIV and AIDS continue to be influenced by the deep and well-coordinated commitment of all service sectors to a comprehensive array of services for infected individuals and their families. Thus, the goals and objectives presented in this section were developed based on the planning work of Part B, other Ryan White HIV/AIDS Program Parts, and non-Ryan White funded entities.

Based on the outcome of the needs assessment process, as documented in earlier sections, the OHA has developed a series of goals, objectives and strategies to help guide service delivery for the next three years in order to:

- Increase the number of people who know their HIV status;
- Decrease the number of new HIV infections; and
- Increase the number of HIV-positive people and those at high risk of HIV who are living healthier lives.

### **Goal 1: Service Provision**

Support and enhance the current comprehensive, coordinated system of HIV/AIDS prevention and care services while evolving new programs for emerging service needs in order to help ensure full access to services for all infected and affected individuals.

**Objective 1.1:** Bring people into care who are living with HIV and not yet in care. Address the needs of those who know their HIV status and are not in care, as well as the needs of those who are currently in the care system.

**Strategy 1.1.1:** Design the State's system to be able to look at data elements across databases, where possible. Conduct matches with the HIV/AIDS Surveillance database and other service utilization databases to help identify individuals who know their HIV status but are not in specific types of care.

**Strategy 1.1.1a:** Review legal and ethical implications of matching data across various databases.

**Timeline:** Ongoing as new databases are considered

**Strategy 1.1.1b:** Consider selected data matches including the HDAP database to the HIV/AIDS Surveillance database, the Medicaid database, Bureau of Substance Abuse Service admissions database, and the Part B client services database to help describe people who are not receiving state-funded medication and adherence support, eligible for but not enrolled in Medicaid, and/or who are lost to care.

**Timeline:** Years 1-3. Ongoing



**Strategy 1.1.2:** Continually assess and enhance early intervention services

**Timeline:** Years 1-3. Ongoing

**Strategy 1.1.3:** Continually assess and enhance linkages to key points of entry into health care system, particularly through correctional facilities, substance abuse and mental health services.

**Timeline:** Years 1-3. Ongoing

**Objective 1.2:** Reduce disparities in HIV care, access, and services among affected subpopulations and historically underserved communities.

**Strategy 1.2.1:** Sustain the current service capacity and develop new programs to address emerging service needs as indicated in this plan.

**Timeline:** Ongoing

**Strategy 1.2.2:** Utilize current procurement processes in client services, counseling and testing, and prevention to expand risk assessment, HIV and STD screening, points of access, referral mechanisms, and client follow-up practices for historically underserved populations

**Timeline:** Ongoing

**Strategy 1.2.3:** Integrate meaningful prevention and behavioral support into clinical care and client services for individuals living with HIV.

**Timeline:** Ongoing

**Strategy 1.2.4:** Examine the differential impact of healthcare reform on African American, Latino, and other underserved populations at risk

**Timeline:** Ongoing

**Objective 1.3:** Address the challenges of multiple co-morbid conditions through enhanced critical case finding, care linkage, and care access and utilization.

**Strategy 1.3.1:** Maintain and increase linkages with both CARE Act and non-CARE Act providers including HIV care, HIV prevention, substance abuse, mental health and housing providers.

**Strategy 1.3.1a:** Continue ongoing collaboration with HIV prevention service providers with particular reference to prevention services for HIV infected individuals and improved risk assessment and referral linkages (including, but not limited to joint funding mechanisms) between prevention and care providers.

**Timeline:** Ongoing

**Strategy 1.3.1b:** Continue Massachusetts HIV Prevention Planning Group (MPPG) coordinated efforts. The MPPG is coordinated by the OHA and managed by its Prevention and Education unit. The MPPG relies on membership recruitment as a primary mechanism to assure coordination with other planning activities. Many

members of the MPPG are also members of the Ryan White Part A Planning Council and the Part B SCCs. In addition, the MPPG's community co-chair has a seat on the Statewide CAB.

**Timeline:** Ongoing

**Strategy 1.3.2:** Improve data gathering on referrals and referral follow-up in all service areas

**Timeline:** Ongoing

**Strategy 1.3.3:** Continue joint funding by the HAB and BSAS of a technical assistance agency to provide a range of HIV education and training programs for substance abuse providers to increase the capacity of programs to serve PLWHA.

**Timeline:** Ongoing

## **Goal 2: Collaboration**

**Objective 2.1:** Maintain collaboration between Ryan White Parts in Massachusetts and consumer/provider partnerships, assuring ongoing and accurate assessment of the changing needs of people living with HIV and the efficient development and dissemination of effective service delivery strategies.

**Strategy 2.1.1:** Review the needs of those affected by HIV/AIDS by working with and reviewing materials produced by planning councils, SCCs, consumer advocacy boards, and through inter-agency mechanisms.

**Timeline:** Ongoing

**Strategy 2.1.2:** Adapt to changing state funding through increased coordination efforts regarding resources and services with Part A Boston EMA

**Timeline:** Ongoing

**Strategy 2.1.3:** Review available services and the prioritization of service categories as established by Part A during their resource allocation process.

**Timeline:** Ongoing.

**Strategy 2.1.4:** Attend and participate on the Boston EMA Part A Planning Council.

**Timeline:** Monthly. Ongoing.

**Strategy 2.1.5:** Continue joint planning efforts with the MDPH Part D program, including increasing the routine HIV counseling and testing of high-risk women through the perinatal program and future planning activities to address the respective roles of Part B and Part D programs in meeting the needs of WICY.

**Timeline:** Ongoing.

## **VII. How Will We Monitor Our Progress?**

## Implementation and Evaluation Plans

### Goal 3: Monitoring, Evaluation & Quality Assurance

**Objective 3.1:** Maintain and enhance existing quality management processes necessary to monitor and evaluate services along the continuum of care.

**Strategy 3.1.1:** Where possible, maximize the collection of common data elements and client identifiers across Departmental service areas

**Timeline:** Ongoing

**Strategy 3.1.2:** Continue to fund special studies and evaluation projects including quality management programs and measures.

**Timeline:** Ongoing

**Objective 3.2:** Continue to review and update, as necessary, documents, guidelines and current systems.

**Strategy 3.2.1:** Review client utilization data to provide feedback to service providers with reference to relative success in reaching prioritized populations

**Timeline:** Ongoing

**Strategy 3.2.2:** Implement joint client services standards of care with the Part A Boston EMA.

**Timeline:** Ongoing

**Strategy 3.2.3:** Periodically review and update as necessary consumer grievance procedures.

**Timeline:** Ongoing

## **Attachment 1. Letter of Concurrence**

## **Attachment 2: Routine HIV Counseling & Testing of Pregnant Women Clinical Advisory Update**



The Commonwealth of Massachusetts  
Executive Office of Health and Human Services  
Department of Public Health  
250 Washington Street, Boston, MA 02108-4619

DEVAL L. PATRICK  
GOVERNOR

TIMOTHY P. MURRAY  
LIEUTENANT GOVERNOR

JUDYANN BIGBY, MD  
SECRETARY

JOHN AUERBACH  
COMMISSIONER

ROUTINE HIV COUNSELING & TESTING OF PREGNANT WOMEN  
CLINICAL ADVISORY UPDATE

TO: Massachusetts Prenatal Care Providers

FROM: John Auerbach, Commissioner  
Lauren Smith, MD, MPH, Medical Director

Date: June 17, 2008

Re: Routine HIV Counseling and Testing of Pregnant Women

---

This Massachusetts Department of Public Health (MDPH) Clinical Advisory Update is meant to provide clarification on national guidelines and outline MDPH recommendations for routine HIV counseling and testing to all women in prenatal care. In 2006, the American College of Obstetrics and Gynecology, (ACOG) ([www.acog.org](http://www.acog.org)) and the Centers for Disease Control and Prevention, (CDC) ([www.cdc.gov](http://www.cdc.gov)) both recommend that **HIV counseling and testing be performed routinely for all pregnant women, without reference to their risk profile**. This is consistent with current MDPH recommendations. The ACOG and CDC recommendations further support the elimination of informed consent for HIV counseling and testing of pregnant women, which is *not* consistent with Massachusetts law. In the Commonwealth, MA General Law c111, § 70F requires written informed consent for HIV testing, forming the basis for the Massachusetts opt-in system of HIV testing.

Massachusetts Routine HIV Counseling and Testing Recommendations:

- **Routine counseling and testing should be provided to all pregnant women** (regardless of the provider's or women's perception of their risk). All pregnant women should be offered HIV testing and tested, with their consent, as part of the routine battery of prenatal lab tests during each pregnancy.
- **Provide all women in prenatal care with printed materials about HIV testing.** The MDPH has developed two documents which are available free of charge for your use. These may be obtained by contacting the MA Health Promotion Clearinghouse at [www.maclearinghouse.com](http://www.maclearinghouse.com):
  - **HIV and Pregnancy: Get Tested. Get Care. Get Support** which provides information on testing during pregnancy, treatment and how to keep your baby safe.

- **Counseling and Testing:** HIV Questions and Answers which provides information on counseling and testing including different types of tests.
- **Obtain written informed consent in accordance with the MA General Law cited above.**  
A consent form may be separate or may be part of a general consent form as long as it is distinct from other tests. A sample consent form is at the end of this document.
- **Provide repeat voluntary HIV testing during pregnancy to those women at continued risk, or who previously declined testing during current pregnancy.**
- **Provide voluntary rapid HIV testing in labor for women with undocumented HIV status** (if positive, confirm with blood draw, initiate treatment, and obtain Infectious Disease consultation).

MDPH is committed to providing assistance to prenatal care providers as they work to observe the Department's recommendations. Given the enormous advances in HIV prophylaxis for pregnant women and newborns, it is clear that early identification and individualized treatment of all pregnant women with HIV is the best way to prevent pediatric HIV disease and maximize maternal health.

The pregnancy of an HIV infected woman should be considered a high risk pregnancy. HIV infected women in prenatal care should also be in the care of a clinician knowledgeable and experienced in the provision of HIV-related care. If the pregnant woman does not already have such care, appropriate referrals should be made. A toll free number (**1-800-742-2211**) has been created to assist providers with referrals and treatment issues (through the Massachusetts Community AIDS Resource Enhancement – MassCARE - Program) ([MassCARE](#)). If no insurance coverage exists for such care, the state-funded Enhanced Medical Management Service (EMMS) ([resource guide](#)) may be utilized. The cost of medications may be covered through the HIV Drug Assistance Program (HDAP) ([HDAP website](#)). In addition, the website [www.aidsinfo.nih.gov](http://www.aidsinfo.nih.gov) has the most current recommendations for treatment of perinatal HIV.

---

### Sample Consent Form – **HIV Testing**

My signature below indicates my consent to have my blood or a swab of my mouth tested for the presence of **HIV (the Human Immunodeficiency Virus)**.

I understand that my test results will be shared with my health care provider, and that if my health care provider diagnoses me with HIV infection or AIDS, she/he is required to submit an HIV/AIDS case report form to the Massachusetts Department of Public Health HIV/AIDS Surveillance Program.

This consent will expire one year from the date it is signed, unless I withdraw my consent in writing before this date.

---

Name (please print)

---

Signature

---

Date

## **Appendix B. List of Participants in the SCSN Process**



# **The Massachusetts SCSN/Comp Plan Working Group 2008**

- Arlene Buck, Brigham & Womens' Hospital (Part D)
- Sandra Broughton, MDPH, CSHCM (Part D)
- Donna Costa, BAMSI (Part D)
- Kevin Cranston, MDPH AIDS Bureau (Part B)
- Donna Gallagher, New England AIDS Education and Training Center (Part F)
- Nancy Galloway, Boston Pediatric and Family AIDS Project, Dimock CHC (Part D)
- Linda Goldman, MDPH AIDS Bureau (Part B)
- Michael Goldrosen, Boston Public Health Commission (Part A)
- Henia Handler, Fenway Community Health Center (Part C)
- Jessica Kraft, Boston Public Health Commission (Part A)
- Laura Kozek, Boston Public Health Commission (Part A)
- Sophie Lewis, MDPH AIDS Bureau (Part B)
- Joe McKee, AIDS Project Worcester (Part A & B)
- Donna Rivera, Greater Lawrence Family Health Center (Parts A, B, C, & D)
- Annette Rockwell, MDPH AIDS Bureau (Part B)
- Helene Bednarsh, Dental Ombudsman Program (Part F)
- Norman Deschaine, Holyoke Health Center (Part B & C)